Introduction
Seven AI/AN Programs reaching almost 100 tribes and urban AI/AN communities are receiving CDC funding for Comprehensive Cancer Control. They are addressing significant goals to reduce cancer inequities. These programs serve as models for other tribes / tribal organizations interested in developing a comprehensive cancer control program.

What’s in the Case Study?
This case study highlights the successes and challenges of seven AI/AN Comprehensive Cancer Control Programs. Summaries of comprehensive cancer control plans are included. You will read about many activities that the programs have implemented, only some of which have been funded by the CDC. Comprehensive cancer control is a collaborative process through which a community and its partners pool financial, human, and clinical resources to reduce the burden of cancer. These collaborations and their accomplishments are described here.

History of Tribal Cancer Control Programs
The National Comprehensive Cancer Control Program (NCCCP) was established in 1998 due to the efforts of public health professionals who recognized that addressing the US cancer burden would require a more collaborative approach. These individuals believed that creating collaboration among existing programs and organizations already involved in the effort to find a cure and meet the needs of patients could affect all aspects of cancer care from prevention and early detection to survival and quality of life. Since its inception, the NCCCP has supported the establishment and growth of coalitions which develop cancer control plans.

The initial CDC pilot program included five states (Colorado, Massachusetts, Michigan, North Carolina and Texas) and the Northwest Portland Area Indian Health Board (NPAIHB). These grantees had existing cancer control plans. Since 1998, the national program has grown to 65 grantees including the 50 states, the District of Columbia, seven AI/AN governments and organizations and seven territories and US-associated Pacific Island jurisdictions. They each have a comprehensive cancer control plan. As the NCCCP has evolved, new priorities and areas of interest have emerged including topics such as survivorship, genomics, and pediatric cancers.

The seven AI/AN CCC Programs include the initial program, NPAIHB, followed in 2004 with four programs, the Alaska Native Tribal Health Consortium, the Cherokee Nation Cancer Control Program, the Fond du Lac Reservation Wiidookaage Cancer Control Program, and the South Puget Intertribal Planning Agency (SPIPA). In 2005, the Aberdeen Area Tribal Chairmen’s Health Board (now the Great Plains Tribal Chairmen’s Health Board) created the Northern Plains Comprehensive Cancer Control Program (NPCCCP) and in 2007 CCC funded the Tohono O’odham Nation. Each of these programs has developed tools and resources that are specific to its own culture and location and, as noted in this Case Study, is making great strides towards reducing the cancer burden for their populations.
Funding
This material was supported through CDC DCPC Cooperative Agreement 1U57DP003084. The content is solely the responsibility of NACR and the authors and does not represent the official views of the seven AI/AN Cancer Programs, CDC or any other federal agency.

Acknowledgments & Editorial Credits
Special thanks to Linda U. Krebs, RN, PhD, AOCN, FAAN, Lisa D. Harjo, MEd, and Linda Burhanstipanov, MSPH, DrPH and the seven AI/AN Cancer Programs.

Disclaimer
This publication should not substitute for professional advice from a healthcare professional. Readers should always consult a physician or other healthcare professional for medical screening, treatment and advice. Please note the phrase “health care provider” also refers to tribal clinic professionals such as a Doctor, a Nurse, a Nurse Practitioner, a Physician’s Assistant and/or a Nurse Midwife.

Native American Cancer Research Corporation is a national non-profit organization dedicated to improving the lives of American Indian and Alaska Natives by helping prevent cancer, detect cancer early and provide the highest quality care and lifestyle for Cancer survivors and their loved ones.

2013 Native American Cancer Research Corporation Case Study Series:
American Indian and Alaska Native (AI/AN) Comprehensive Cancer Control Programs: Successes, Challenges, Goals and Future Directions

Contents:
History of Cancer Control Plans ..............................................Cover
NCCCP Priorities .................................................................1
Northwest Tribal Cancer Coalition Leads to Tobacco Control Policies.................................................................1
Successful Outreach Strategies ..............................................2
Encouraging Colorectal Cancer Screening .................................2
Alaska Natives Conquering Obesity and Learning to Eat Well....................................................................................3
Reaching the Community .......................................................3
Tribal Cancer Control Plans ....................................................4-6
Challenges ...........................................................................6
Future Directions ..................................................................6
Endnotes ..............................................................................6
National Comprehensive Cancer Control Program (NCCCP) Priorities

“The NCCCP’s success is grounded in partnerships that reach across traditional divides to make comprehensive cancer control a reality in communities across the nation.”

NCCCP Priorities:

• Emphasize primary prevention of cancer
• Coordinate early detection and treatment activities
• Address public health needs of cancer survivors
• Use policy, systems, and environmental changes to guide sustainable cancer control
• Promote health equity as it relates to cancer control
• Demonstrate outcomes through evaluation to improve programs

For more information about the National Comprehensive Cancer Control Program, visit http://www.cdc.gov/cancer/ncccp/about.htm.

Northwest Tribal Cancer Coalition Leads to Tobacco Control Policies

Cancer control for American Indian and Alaska Natives in Idaho, Oregon, and Washington encompasses 190,000 AI/AN tribal members, 43 local tribes with three distinct cultures, and representatives from other tribes. This was the challenge facing the NPAIHB in creating cancer control policies and community-wide cancer plans.

During their initial funding cycles from CDC, the NPAIHB created the Northwest Tribal Cancer Coalition (NTCC). The coalition was created to build partnerships and provide a forum for networking and sharing information on resources, screening, educational, clinical, and policy updates. Subsequent funding allowed the coalition to train northwest tribal

Native American Rehabilitation Association New Year’s pow wow honoring cancer survivors.

programs to affect change, and provide national, regional, state and local cancer data, research, and evaluation tools for making decisions about cancer prevention and control.

Through the continued efforts of the coalition, individual tribes have continued to establish tobacco free policies in their communities, implement prevention programs through education and outreach activities, and promote early detection through screening programs.

NTCC also produced several products for community members and health professionals facing cancer. The products include resources for medical services and support services for patients. (Northwest Tribal Cancer Resource Guide, http://www.npaihb.org/images/projects_docs/TribalResourceGuide1-23-07Final4Web.pdf.)
Successful Outreach Strategies: Educating through Community Events and Social Media

Successful outreach strategies are an essential aspect of comprehensive cancer control. The South Puget Intertribal Planning Agency Cancer Control Program (SPIPA) focuses on preventing cancer through providing resources and information to the communities within the SPIPA consortium tribes. Culturally appropriate cancer-related tools and media messages from local communities are the platform for providing information and creating awareness.

Quarterly community newsletters give updates on cancer control activities, a calendar of events that includes information on both wellness and survivorship programs, cancer support groups, and cancer education events. The tribe also publishes booklets for community members about cancer topics. “Making the Choice” is a booklet about dealing with the different stages of prostate cancer.

Cherokee Nation reaches its members through community education and health fairs, giving each event a focus on a specific type of cancer. Each event includes activities and provides promotional materials that focus on awareness and the importance of screening. An example of promotional materials is calendars with information on breast awareness and annual mammography. The program also uses social media such as YouTube, Twitter, and Facebook and is beginning to develop digital storytelling to communicate primary cancer prevention messages. (ANTHC uses health fairs, social media and digital storytelling also)

The Tohono O’odham hold annual rodeos with the last two promoting breast cancer awareness through “Tough Enough to Wear Pink” (TETWP), theme. Contestant and rodeo participants were encouraged to wear pink and many did. The 1st Annual Men’s Wellness event was held that focused on men specific cancer that was well attended.

Encouraging Colorectal Cancer Screening through the Rollin Colon’ and Nolan the Colon

Increasing colon cancer screening among American Indians/Alaska Natives can prove to be a challenge that is complicated by a lack of knowledge and awareness regarding colon cancer risks, screening procedures, and lack of access to clinical services. Fear of a cancer diagnosis is also a known barrier.

The Northern Plains Comprehensive Cancer Control Program (NPCCCP) and the Alaska Native Tribal Health Consortium (ANTHC) are using innovative means to address insufficient knowledge and encourage colon cancer screening. They are using an educational tool that is designed to resemble a colon. Community members walk through an interactive, inflatable colon that is approximately 10 feet tall and 25 feet long. They see a healthy colon and how precancerous polyps can grow into colorectal cancer. The inflatable colon is used at tribal community events, health fairs, powwows and educational events. 

The NPCCCP uses the Rollin’ Colon to educate AI communities about colon cancer risks. Pre and post test questions assess knowledge before and after walking through the colon. Information is provided to promote colorectal cancer awareness and screening. The survey results reflect at least a 25% increase in knowledge.

The Alaska Native Tribal Health Consortium uses Nolan the Colon to reach Alaska Natives.
Through a coordinated effort promoting the importance of colorectal screening, the Alaska tribal health system has increased the rate of screening in the Alaska Native people from 52% to 68% in 2012. Nolan is similar to the Rollin’ Colon, and is available for use by local programs throughout Alaska. 

**Alaska Natives Conquering Obesity and Learning to Eat Well**

Many of the Comprehensive Cancer Control Programs have a focus on improving nutrition and healthy eating. Two, in particular, are working towards reintroducing local foods into daily meal planning. ANTHC has created two publications focusing on Native foods and healthy eating. The first, Traditional Food Guide for Alaska Native Cancer Survivors, is a guide to identifying local food sources. It provides information on the nutrients, calories and serving sizes of subsistence foods from the land, water, and plants such as caribou, sea asparagus and wild berries. Recipes and information about using these foods during and following cancer treatment is included. The guide is in its third printing with over 11,000 distributed. The second publication is an activity book for children in Grades 3 and 4, Traditional Food Guide Activity Book. The book encourages healthy eating and makes learning about nutrition fun. Children are given information about portion sizes and how to read nutrition labels. It is also in its third printing with over 15,000 distributed and over 60 schools throughout Alaska using the book.

The Tohono O’odham Nation (TON) recognized that healthy living was a way of life that required an infusion of support from within and outside of its geographical boundaries. In support of this thinking, the TON have been reintroducing locally grown foods into their daily diets and increasing physical activities at health events and during afterschool activities. Moreover, due to diabetes and its relationship with cancer, presentations are being developed and taken out to various venues describing how healthy living combined with prevention methods such as mammography and colonoscopies can potentially reduce the numbers of cancer diagnosis on the Nation.

The Tohono O’odham Nation is working towards reintroducing local foods into daily diets. It has developed a program, Healthy O’odham Promotion Program (HOPP), which focuses on diabetes, but has relevance to the cancers that are linked to obesity, diet, and physical activity. The TON has built seven fitness centers to improve access to exercise facilities and health education. In collaboration with HOPP, the Cancer Control Program has made great strides, with the incidence of obesity plateauing and cancer screening increasing.

**Reaching the Community through One-on-One Cancer Support and Education**

Reaching those who need cancer education, support and resources is a focus of the Fond du Lac cancer control program. Using a Cancer Outreach Worker who has detailed knowledge of the community and its resources, patients and their families can receive one-on-one support. This support is available from the moment patients are aware of an abnormal test through diagnosis, treatment, and through the end of life when the cancer is terminal. The Cancer Outreach Worker provides support services through home visits and telephone consults as well as providing small group education and support at Tribal community centers, health fairs and community events. Having a booth at each event allows the Outreach Worker to educate about cancer, particularly the need for cancer screening, and to be visible to community members.

As evidenced by the number of people using the Cancer Outreach Worker’s services, she is both familiar with and trusted by the community. Successful navigation of patients leads to fewer financial and access barriers, and increased support services which improves cancer outcomes and increased quality of life.
Goals and Objectives from Tribal Cancer Control Plans

Alaska Tribal Health System Comprehensive Cancer Control Plan, 2005-2010

Goals:
- Prevention: Work together to prevent cancer among Alaska Natives
- Early Detection: Detect conditions that may lead to cancer; Find cancer in its earliest stages.
- Diagnosis: Diagnose cancer using the least invasive and most comprehensive procedures.
- Treatment: When cancer is diagnosed, treat the patient and family with the most appropriate therapy as close to home as possible.
- Survivorship: Alaska Native cancer patients and their families will have access to programs and services that address their physical, mental, and spiritual needs to improve the length and quality of life. Access will include addressing the practical issues cancer survivors face on a daily basis during and after cancer treatment.
- Palliative Care: Alaska Natives diagnosed with cancer will have the access to culturally appropriate palliative care services; Alaska Native cancer patients will have the choice of spending the last part of their life at home or close to home with culturally appropriate physical, spiritual emotional and community support.
- Surveillance & Research: Collect complete, accurate, and timely data on cancer in Alaska Natives.

Cancer Plan Available at: http://ccplanet.cancer.gov/state_plans/Alaska_Native_Tribal_Health_Consortium_Cancer_Control_Plan.pdf

Cherokee Nation Comprehensive Cancer Control Plan II 2005-2007

Goals:
- To assist in addressing the cancer needs in Cherokee Nation through prevention, education and early detection, and to insure cancer patients receive:
- Quality care when accessing treatment
- Improved access to clinical trials
- Patient advocates and/or navigators
- Palliation assistance through hospice and other community health care programs.
- Website: http://cancer.cherokee.org/


Fond du Lac Band of Lake Superior Chippewa - Wiidookaage Cancer Plan, 2007-2012

Goals:
- Maintaining cancer databases and a Fond du Lac Cancer Registry,
- Promoting and practicing lifestyles that will prevent cancer,
- Promoting access to regular cancer screening tests to facilitate the diagnosis of cancer early, when it is most treatable,
- Providing support to people with a cancer diagnosis and their families immediately upon diagnosis,
- Ensuring access to the best possible cancer treatment options,
- Maximizing the quality of life for the person with cancer,
- Providing comprehensive, compassionate end-of-life care,
- Mobilizing cancer survivors to share their collective wisdom,
- Providing education about prevention, early detection, treatment, survivorship, palliative support and care,
- Creating support systems for caregivers, and
- Establishing and maintaining the effective evaluation process necessary to track progress and advance the comprehensive cancer program.
- Website: www.fdlrez.com

Cancer Plan Available at: http://ccplanet.cancer.gov/state_plans/Fond_du_Lac_Cancer_Control_Plan.pdf
**Northern Plains Native American Comprehensive Cancer Control Plan, 2008-2012**

**Goals:**
- Reduce the incidence and mortality rates of cancer in Northern Plains American Indian communities by promoting healthy lifestyles and reducing cancer related risk factors.
- Increase appropriate cancer screening for Northern Plains American Indians so cancer is detected at earlier stages.
- Ensure that all Northern Plains American Indians with cancer receive access to quality western and traditional cancer care services and aftercare.
- Assure that Northern Plains American Indian cancer patients, their families and their caregivers will have access to programs and services that address their physical, mental, and spiritual needs to improve the length and quality of life.
- Assure the best quality of life and access to needed comfort care services for Northern Plains American Indians affected by cancer, their families and their caregivers.
- Ensure a sufficient and competently trained workforce who can provide culturally sensitive/competent comprehensive cancer care for the Northern Plains Tribes.
- Make complete, accurate and timely data on cancer available and accessible to the Northern Plains American Indian tribal communities in order to inform and improve health status.
- Increase awareness of cancer research projects and facilitate clinical trials and community-based participatory research to improve cancer health status.


**Northwest Tribal Comprehensive Cancer Program, 2007-2027**

**Goals:**
- Facilitate a process for Northwest tribes to promote cancer risk reduction strategies.
- Provide information on the most current early detection, screening and treatment practices through education and resource materials.
- Provide education regarding quality of life for cancer patients, their families and caretakers.
- Coordinate and collaborate with local and national cancer organizations and individuals.
- Improve Indian-specific cancer control data.
- Website: [http://www.npaihb.org/programs/nw_tribal_cancer_control_project/](http://www.npaihb.org/programs/nw_tribal_cancer_control_project/)


**South Puget Intertribal Planning Agency (SPIPA), 2005-2012**

**Goals:**
- Provide cancer prevention by increasing awareness through education for AI/AN and community members at all SPIPA Tribes.
- Detect all screenable cancers at the earliest stage for tribal and community members at all SPIPA Tribes.
- Ensure that tribal and community members with cancer at all SPIPA Tribes receive cancer treatment services that are state of the art, timely, comprehensive, traditional and affordable.
- Ensure that tribal and community cancer survivors and their loved ones at all five tribes receive support (Cancer survivors include family, caregivers, friends and other support services).
- Website: [spipa.org](http://spipa.org)

Tohono O’odham Nation Comprehensive Prevention and Control Plan 2010-2015

Goals:
- Promote risk reduction for the Tohono O’odham Nation through primary prevention
- Maximize community acceptance and timely utilization of available cancer screening services to increase the likelihood of early diagnosis and positive outcomes
- Increase access to appropriate and effective diagnosis and treatment services
- Improve the quality of life for Tohono O’odham Nation members
- Improve support available to cancer survivors and their family members as co-survivors
- Increase educational and support services for children affected by cancer
- Improve knowledge of known environmental risk factors


Challenges to Meeting Cancer Control Priorities

AI/AN Cancer Control Programs face challenges implementing cancer control plans and reaching the populations most in need. Across all programs, limited funding and access to resources are barriers to carrying out identified strategies for cancer control. Competing healthcare priorities within healthcare and social service delivery systems and lack of capacity and resources are current issues facing most AI/AN communities as well increasing the capacity to manage cancer control projects. For the people served by these cancer control programs, the primary focus is on meeting basic needs (food, shelter, clothing). Cancer prevention and early detection are of much lower concern. Additionally, lack of knowledge about cancer, cancer treatment, and survival impedes the potential impact of cancer screening efforts.

Future Directions

Each tribal program has identified future directions that are aligned with the priorities of the National Comprehensive Cancer Control Program. In 2010 the national program identified six priorities that built on previous successes and span the cancer control continuum. The six national priorities are to emphasize primary prevention; coordinate early detection and treatment activities; address public health needs of cancer survivors; implement policies to sustain cancer control; eliminate health disparities to achieve health equity; and to use evidence and measure impact through evaluation. Tribal programs will work to increase screening rates by supporting screening programs. They will work towards tobacco-free venues and increasing tobacco messages and cessation services. They will increase the numbers of youth who receive HPV vaccinations. Tribal programs will focus on education of community members and healthcare providers by implementing education summits and community programs that include Native Cancer 100 and the new Native Cancer 101 education modules. The programs will continue to support healthy lifestyle programs, and to support cancer survivors and their caregivers.

Endnotes

6 Alaska BRFSS 2008-2012.